

*Next Meeting – Monday, January 8, 2007 – 2 PM
Appoquinimink State Service Center
Middletown, Delaware*

**STATE COUNCIL FOR PERSONS WITH DISABILITIES
BRAIN INJURY COMMITTEE
November 6, 2006 – 2:00 PM
APPOQUINIMINK STATE SERVICE CENTER
MIDDLETOWN, DELAWARE**

PRESENT: John Goodier, Chair; Brian Hartman, Co-Chair;; Dianne Bingham, DPC; Ray Brouillette, Easter Seals; Dr. Jane Crowley, A.I. DuPont Hospital; Adam Fisher, DOE; Malik Harris, DelArf; Linda Heller, DSAAPD; Tony Horstman, SCPD; Dr. Dan Keating, Bancroft Neurohealth; Lora Lewis, DPH; Chris Long, DDDS; Mike Merrill, VR/U.S. DVA; Tom Parvis, DVR; Ann Phillips, Parent; Al Rose, DDC; Liz Schantz, Consumer; Mary Soligo, Christiana Counseling and Kyle Hodges, Staff

ABSENT: Dr. Jackie Christman, DPH; Virginia Corrigan, Christiana Care; Aaron Deede, Consumer; Janet Leitch, Consumer; Beth Mineo Mollica, DATI; Beverly Stapleford, CDC; Wendy Strauss, GACEC and Dawn Stewart, Healthy Living

GUESTS:

Laura Cygan, EMSC/A.I. DuPont Hospital/Parent Advocate
Barbara Geiger-Parker, New Jersey Brain Injury Association
Larry Smith, Deputy Director, DSAAPD
Scott Ponamen, Consultant

CALL TO ORDER

The meeting was called to order at 2:05 PM.

APPROVAL OF MINUTES

Motion was made, seconded and approved to accept the September 11, 2006 meeting minutes as submitted.

AGENDA ADDITIONS/DELETIONS

BUSINESS

Waiver Update

Larry Smith and Scott Ponamen reviewed the power point presentation and provided the following additional information:

- The Assisted Living Waiver has been submitted to CMS and it has been approved.
- By Thanksgiving, the initial part of the work will be completed. This will encompass define the need in Delaware in terms of what services need to be developed and implemented as well as the definition of the to be served. In addition, it will address how DSAAPD develops medical necessity criteria around that.
- Then, DSAAPD will collaborate with CMS over the next couple of weeks and finalize that strategy. Then they will move into the actual waiver amendment application process.
- Today we will review the ABI Waiver Strategy and Timeline, CMS Update, DSAAPD/DMMA approach and a status report of the accomplishments to date as well as what the next key steps will be.
- Scott added that for the DSAAPD/DMMA approach (Phase II: Amendment Development & Submission) --this will be started by the end of November 2006.
- Under the Population and Benefits Work Group, Scott added that they actually visited the New Jersey Brain Injury Association (NJBIA) to do an external assessment. New Jersey targets the entire acquired brain injury population. Some State's services were developed and implemented, but never utilized.
- The six states that were used as benchmarks were chosen because DE wanted to look at the programs that were more broader and long term.
- Also, under "Methodology—External Assessment", Scott added that they looked at the Rancho Los Amigos—Levels of Cognitive Functioning Scale. They met with several providers to walk through that instrument which is used by New Jersey in their Medicaid program to assess people who have the greatest opportunity for improvement from each of the different types of services that are available.
- The "Findings—External Assessment" table actually summarizes, at a high level, what was looked at. In meeting with New Jersey, they have a trust fund through motor vehicle taxing or surcharge where they are able to provide services outside of Medicaid to clients with brain injury with a certain lifetime maximum and an annual maximum (limited amount). Scott added that for those persons caught in the middle or waiting for eligibility, this would be a safety net.
- Also under "Findings—External Assessment", 8 services were approved by CMS for the ABI waiver. Several were not able to be operationalized because there were challenges and there were several that no providers were available to deliver services. Funding Concerns—if we could build the funded needed into the actual rates, then we would be getting Federal funding match. Brian suggested having a supplement to the MAP 25 Level of Care.
- Kyle added that a small group of the BIC contributed some recommendations to the Findings—External Assessment survey via a letter to Allan Zaback. Scott noted that they were incorporated into the final findings for the survey.
- Under "Targeted Population", Scott noted that they will be coming to the next BIC meeting to update the committee in more detail on the medical necessity definition and the criteria for which the targeted population will be.

- Under the “Recommendations” chart, although not shown, Scott added that the State Plan services have to be better coordinated for this population. The total strategy is not which waiver services are added, but doing a better job at coordinating services that are already available through the state plan for all Medicaid persons—which is part of the focus.
- Also under the “Recommendations” chart, Assistive & Special Medical Equipment, people with brain injuries need to be identified consistent with equipment needs. If the equipment is ordered and demonstrated by a physician to be medically necessary, then that piece of equipment needs to be provided through the State services.
- Under “Additional Recommendations” regarding the issue of “developing credentialing program for providers”, DSAAPD needs to work with the BIAD, the U of D Center for Disabilities Studies and with the state staff to determine if the case managers are experts in the brain injury population. They need to help them by re-enforcing the most recent technologies.
- Also, the “Finance and Provider Work Group” was developed to do the feasibility assessment from the monetary prospective. Are they meeting the requirements from CMS in terms of budget neutrality and looking at the dollars available to provide services.
- Key Next Steps regarding the “Submission of Waiver Amendments—3/31/07” - this waiver will be run like the assisted living waiver. A group of consultants from CMS have been sub-contracted. DSAAPD will provide it to a week early so CMS can do an informal review, give Scott their feedback, and then the actual formal final submission will be smoother. Scott added that they went to CMS in Maryland’s Central Office to engage them in reviewing our application which helped their creditability in having waivers approved quickly.
- Brian said that at an earlier meeting, it was discussed if kids are going to be covered and asked if a decision has been made in this context. Larry said that the DSAAPD statute mandates that they cover persons 18 years and older. Kyle noted that Larry had sent an e-mail stating that the affected divisions will be contacted to develop an informed response to the question of kids being covered. Larry said that they have discussed this with DDDS about serving this population. Input was received from DDDS; however the DSAAPD statutory mission must be followed. Linda added that during the second year of the grant requires that DE, explore the idea of the children’s TBI waiver. Lora added that this was to start in the first year and carried over to the second year of the grant.
- Scott added that the gray area is ages 18-22 and DSAAPD is in the process of finalizing a MOU with the DDDS.
- Larry added that the State will provide \$360,000 match. Brian would like to advocate at the DHSS budget hearing for the state match or more in the FY 08 budget.

Presentation from the New Jersey Brain Injury Association—Barbara Geiger-Parker

Barbara passed out a brief explanation of the New Jersey waiver and presented the following information.

- The waiver was established about 12 years ago. There are 350 persons in their waiver. This is not for people in assisted. The maximum for those in a group home is \$9,500 per month. If you live in your own home, you can get support and services up to a maximum of \$7,500 per month.
- In NJ, there are two primary service providers for people with brain injury. If you are injured before you are 22, the DDDS is the waiver that you would be using; and if you are injured after the age of 22, you would be using the TBI waiver that is administered by the Division of Disability Services.
- Barbara passed out the information bags that are distributed to the hospitals.
- Barbara noted that when NJ's DMR became DDD, there was an investment by the state in a number of organizations that are not mental retardation but are developmental disabilities. Therefore, there are pretty strong groups of Autism, Spina Bifida, Epilepsy, Cerebral Palsy and Brain Injury.
- The NJ state government provides a lot of services that are traditionally covered by the BIA.
- NJ has 10 basic support groups staffed by volunteers.
- NJs Community Services grant pays for their website, newsletter, and a lot of basic services for the BIA. Therefore, the NJBIA could grow in other areas since they didn't have those expenses.
- NJ provides a week of respite for 40 adults with brain injury—funded by the DDDS—there is a cost share.
- Also, the DDDS provides family support which is a care coordination opportunity that is trying to help families identify what their needs are and ways to meet those needs. Four people in the State are working in this area.
- NJ is working with the hospital discharge planners, social workers, and emergency room nurses staff trying to get them to give out a pamphlet on brain injury.
- Through legislation, NJ has a BI Trust fund. NJ added a surcharge to the car registration fees. Motor vehicle accidents are the most common kind of brain injury. The NJ Department of Transportation added a mandatory 50 cents to all car registration fees which generates \$3.6 million a year. The primary purpose is to help people with brain injury obtain post acute services that cannot be obtained from any other place. There is a maximum of \$15,000 a year for services with a life time maximum of \$100,000. This service has been provided the last two years and it is housed within the NJ DDDS. The most requested service is cognitive remediation which is not paid for in many places. Care coordination is also a service that is provided a couple of hours a month – this is requested for people to find service providers and address other difficulties in people's lives. A greater people applying for services are low income—there is a \$100,000 asset limit. This helps those people of low and medium income who make too much money to qualify for Medicaid but don't have enough money to purchase the extra services that are needed. This fund works with acquired brain injury.

- NJ named the NJBIA the coordinator of providing information to people and prevention education.
- Regarding children with TBI being identified and served, NJ has a children and adolescent committee that works on return to school issues. Kyle stated that DE had legislation signed for a specific unit account for children with TBI. Information from the NJBIA and other sources were helpful in making inroads in this area. The NJBIA has coordinated with Rutgers University Continuing Education to create a distance learning course that will be offered on their website free of charge.
- The Brain Injury Association of America has a program called American Academy of Certified Brain Injury Specialists. The NJ waiver services are brain injury programs certified by CARF (Accreditation of Rehabilitation Facilities) and are residentially licensed. With the Minnesota's BIA's permission, the NJBIA borrowed and changed one of their programs called Brain Injury Basics for Families. Once a month, in a different state location, the NJBIA offers a free 2 hour training for parents, families and people with brain injuries on what it means to live with a person with a brain injury.
- The NJBIA last grant focused on vocational issues. There is a publication handout today on the Workforce Development System. A vocational counselor is on staff providing technical assistance to most of their workforce development centers. With some additional funding, this project has been continued and now some systems have changed. In Atlantic County, the NJBIA has a partnership with the County Division of Vocational Rehabilitation Services. Each person that has a brain injury that is seeking services from that County has to have a recent neuro-psychology test or DVR will pay for such a plan. Once the plan is being developed to help the person return to work or seek new employment, the services of a neuro-psychologist as a consultant are available throughout that process. It was stated that for ten years, Delaware has had a neuro-psychologist on staff.
- New Jersey has the following good safety legislation initiatives: mandatory motorcycle helmet law; primary seatbelt law; bike helmet law and also child car seat law. Human Services is the lead in NJ and the Medicaid Program is housed under Human Services. If you prevent other type of injuries, you often times prevent brain injury.
- New Jersey also has a Brain Injury Research Act that is also bringing in about \$3.6 million based on increases of traffic fines. There is also a Spinal Cord Injury Research Act also and the money is to be used to help find a cure for brain injury. Linda noted that there is a Spinal Cord Injury Control Prevention Plan on the table for DE and it is a work in progress. There is a Trauma Registry from the hospitals in both states; however, more funding is needed to take it to the next step for TBI.
- The NJBIA has about 25 employees with 3 being part-time and their budget is \$1.6 million. They raise about \$250,000 and the Kessler Grant (Vocational Grant) is about \$100,000. Forty percent of the \$1.6 comes from the TBI fund and the rest of funding from the state of NJ.
- Three important steps are: 1) Medicaid Waiver; 2) strong relationship between BIA and State government, and 3) having a TBI fund. If all these things are in place, people with brain injury are served as well as they can be at this time.

- The NJBIA has been encouraging the positive ticketing program which is, if a police officer sees children with their helmet on they give the younger children a ticket for free ice cream or a pizza; and the older children a ticket to an electronics store.
- The BIC thanked Barbara for coming and doing a presentation at today's meeting.

PATI Report

I. HRSA EDUCATIONAL PACKET SERIES

HRSA has issued two new sets of educational materials: 1) A Look at TBI Trust Fund Programs; and 2) Traumatic Brain Injury Screening: An Introduction.

A. TBI Trust Fund Programs

This 123-page document provides an overview of TBI trust programs that have been established in 19 states. Such programs are most commonly linked to a surcharge on traffic violations and provide a revenue stream for TBI programs. Brian will share my display copy with the Committee to facilitate review.

B. TBI Screening

Brian provided a short document and some sample screening instruments which may be of value to agencies wishing to adopt or revise TBI screening tools. It may also be of value to DHSS in revising Medicaid waivers to accommodate persons with TBI. The current screening forms used to assess medical eligibility for the waivers are often oriented towards persons with geriatric profiles and may not be very useful tools in assessing TBI.

II. GACEC LEGISLATIVE RECOMMENDATIONS

Consistent with an October 13, 2006 memo, the GACEC has submitted recommendations to the Delaware Department of Education for inclusion in the Department's legislative priorities. The memo includes the following recommended priority: "Advocate for funding for teacher development in the identification and instruction of students with the most challenging service needs, such as *Traumatic Brain Injury*, Autism Spectrum Disorders and children with challenging behaviors."

III. CONCUSSION ARTICLE

A September 25, 2006 News Journal article provides an overview of sports concussions. One promising study is being conducted at the University of North Carolina. Football team members' helmets are equipped with a sensor which measures the magnitude of impact of a hit to the head. An electronic signal is sent to the sidelines where it is recorded on computer. Overall, awareness of the dangers of concussion appears to be growing among players and coaches.

IV. BLOOD SUBSTITUTES & TBI

An article from the November issue of Popular Science highlights a small (8 person) trial of a blood substitute (Oxycyte) for TBI. In head trauma cases, swelling and inflammation often cut off the supply of oxygen to the brain, suffocating brain cells. Oxycyte carries oxygen 50 times as effectively as blood. The drug's tiny particles carry oxygen through damaged vessels too narrow for red blood cells to squeeze through. In animal tests, the compound cut the effects of brain damage in half. Proponents are promoting a larger trial of "oxygen therapy" in emergency rooms.

ANNOUNCEMENTS

The next meeting will be held on January 8 at 2 pm at the Appoquinimink State Service Center in Middletown.

ADJOURNMENT

The meeting was adjourned at 4:10 PM.

Respectively submitted,

Kyle Hodges
SCPD Administrator